

Review

What do we know about the application of the Mental Capacity Act (2005) in healthcare practice regarding decision-making for frail and older people? A systematic literature review

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What is known about this topic

- Staff working in healthcare settings are required to have an understanding of the MCA since it entered into effect in 2007.
- There is a paucity of evidence from family carers about their knowledge of the Act.

What this paper adds

- A detailed literature review for the evidence examining understanding by healthcare professionals of the MCA when providing care for frail and older people.
- A synthesis from the perspectives of lay carers and those involved in providing information and advice about the MCA.
- Evidence that there is a need for improved knowledge and conceptualisation of the Act by healthcare professionals to enable successful incorporation of the Act into everyday care provision in England and Wales.

Abstract

In England and Wales, decision-making in cases of uncertain mental capacity is regulated by the Mental Capacity Act 2005. The Act provides a legal framework for decision-making for adults (16 and over) who are shown to lack capacity and where best interest decisions need to be made on their behalf. Frail older people with cognitive impairments represent a growing demographic sector across England and Wales for whom the protective principles of the Act have great relevance, as they become increasingly dependent on the care of others. However, while the Act articulates core principles, applying the Act in everyday healthcare contexts raises challenges for care providers in terms of interpretation and application. This paper presents a review of the published evidence documenting the use of the Act in healthcare practice, with particular reference to frail older people. Our aim was to identify, review and critically evaluate published empirical studies concerned with the implementation and application of the Act in healthcare settings. A systematic approach was undertaken with pre-determined exclusion and inclusion criteria applied across five electronic bibliographic databases combined with a manual search of specific journals. This review reports on 38 empirical sources which met the inclusion criteria published between 2005 and 2013. From the 38 sources, three descriptive themes were identified: knowledge and understanding, implementation and tensions in applying the Act, and alternative perspectives of the Act. There is a need for improved knowledge and conceptualisation to enable successful incorporation of the Act into everyday care provision. Inconsistencies in the application of the Act are apparent across a variety of care settings. This review suggests staff need more opportunities to engage, learn and implement the Act, in order for it to have greater resonance to their individual practice and ultimately benefit patient care.

Keywords: everyday decision-making, fluctuating capacity, frail older people, Mental Capacity Act, systematic literature review

Background

In England and Wales, decision-making in cases of uncertain mental capacity is now regulated by the Mental Capacity Act 2005 (MCA; entered into effect in 2007). Under the Act a Code of Practice provides a legal framework for decision-making for adults (16 and over) who are shown to lack capacity and where best interest decisions are made on their behalf with a presumption that all adults have capacity to make decisions (Department for Constitutional Affairs, 2007). In this way, the Act provides a means to safeguard the person-centred values that are prioritised by service users (Department of Health, 2012), including opportunities for shared decision-making, and has potential to redress inequalities for those who have uncertain capacity. These individuals will often be frail, older people with cognitive impairments (Samsi & Manthorpe 2011) who represent a growing demographic across England and Wales (Jagger *et al.* 2006, Office for National Statistics, 2012). Indeed it is estimated that in the UK, those aged 75 and over often live with three long-term health conditions (Health Service Journal, 2015). This often results in individuals requiring continual health and social care support.

Across England and Wales, services have had to develop policies to guide implementation of the Act with the Code of Practice providing guidance to anyone who is working with and/or caring for adults who may lack capacity to make particular decisions (Department for Constitutional Affairs 2007, p. 1). However, little is known about how the Act is applied in practice. Research at the time of enactment suggested that there was much confusion among health and social care professionals, with negative implications for implementation (Willner *et al.* 2011). Subsequent studies have examined use of the Act in various contexts: care homes (Manthorpe *et al.* 2011), community nursing (Samsi & Manthorpe 2011), 'housing with care' schemes (Manthorpe & Samsi 2012b), specialist palliative care (Harris & Fineberg 2011) and acute services (Sorinmade *et al.* 2011).

The MCA applies to a range of practices and decision-making – from 'big decisions' about end-of-life treatment (Chapman & Makin 2011) to day-to-day support decisions (Dunn *et al.* 2009). This latter application of the Act – to everyday 'small acts of care' (what to eat, drink, etc.) (Stanley & Manthorpe 2009) – has received scant consideration but can be among the most troubling and burdensome for those delivering care. This observation is supported by the findings from a recent survey of lay carers (Alzheimer Scotland, 2012) which highlighted conflicts and

uncertainties around assessing capacity and promoting autonomy on a day-to-day, decision-by-decision basis. These small acts of care are central to the daily practice of health and social care professionals, represent a priority to informal carers of those who may lack capacity and they cumulatively determine the quality of life of the individual being cared for (e.g. Miranda-Castillo *et al.* 2010). The review set out to identify the empirical knowledge base in this area and to identify where further work is required if we are to appropriately implement the Act in everyday health and social care practice and positively impact the care experienced by frail older people who often suffer complex healthcare needs linked to their age.

Aim

To undertake a systematic review of available empirical literature pertaining to implementation of the Mental Capacity Act within health and social care services with particular reference to frail older people and everyday acts of care.

Methods

The review, conducted during 2013, included a wide range of publications, including qualitative, quantitative and mixed methods research; the primary research included in this review related to practice in England and Wales; and areas in which decision-making is regulated by the Act. The review was conducted by three researchers (KHS, RF, GW) and shared among the project steering group, in order to ensure consistency of approach, and to assess quality of included studies, an agreed protocol was designed at the outset of the review and was monitored throughout. A systematic framework was applied to the search.

Inclusion criteria

- Empirical work or literature reviews undertaken where the protective powers of the MCA, 2005 are applicable (England and Wales, UK)
- Work undertaken from 2005 to 2013
- Work that relates to decision-making with frail and older people at risk of fluctuating, or loss of mental capacity

Exclusion criteria

- Studies relating to learning disabilities, unconscious state, imprisonment and mental health problems

- Commentary papers, reports and discussion papers
- Studies that reported on issues of capacity to consent to research

Search strategy

The following databases were searched: Embase, Medline, Cumulative Index of Nursing and Allied Health Literature (CINAHL), PsycINFO, Cochrane Library.

The search strategy combined two key concepts, MCA and frail older people, and the search framework contained multiple related key words to represent each concept (e.g. 'Lack of mental capacity', 'Fluctuating mental capacity', 'Indeterminate mental capacity', 'Mental Capacity Act', 'Best interest', 'Frail older person'). Terms for the target population (e.g. 'frail', 'elderly', etc.) and phenomenon of interest (e.g. 'mental capacity', were grouped separately using OR and then combined using AND operators. This approach yielded 114 relevant papers after removing duplicates. To further develop the search strategy, additional key terms were identified from the initial search studies and following up relevant citations from identified sources providing a further 24 papers for review and a hand search provided 21 more sources. Results of searches were managed using Endnote V.X10. The research team identified a process for screening and reviewing articles as shown in Figure 1.

Data extraction, review and synthesis

After removal of duplicates, KHS, RF and GW reviewed 138 titles from the search of five electronic bibliographic databases. Another 24 titles were found through the manual search and a total of 159 titles retained. Available abstracts for these titles were then screened using the inclusion criteria. The inclusion criteria was agreed by the study team at the beginning of the review and maintained throughout the process. Of the 159 abstracts that met the inclusion criteria, 51 full manuscripts were retrieved for screening. One source was not available within the time limit for this review, and was, therefore, excluded. One source provided no study protocol so was rejected and a further 11 upon examination and agreement by the team did not meet the inclusion criteria. The 38 sources that remained were rigorously assessed by the three researchers (KHS, RF, GW). A similar framework used for systematic reviews (PRISM Preferred Reporting Items for Systematic

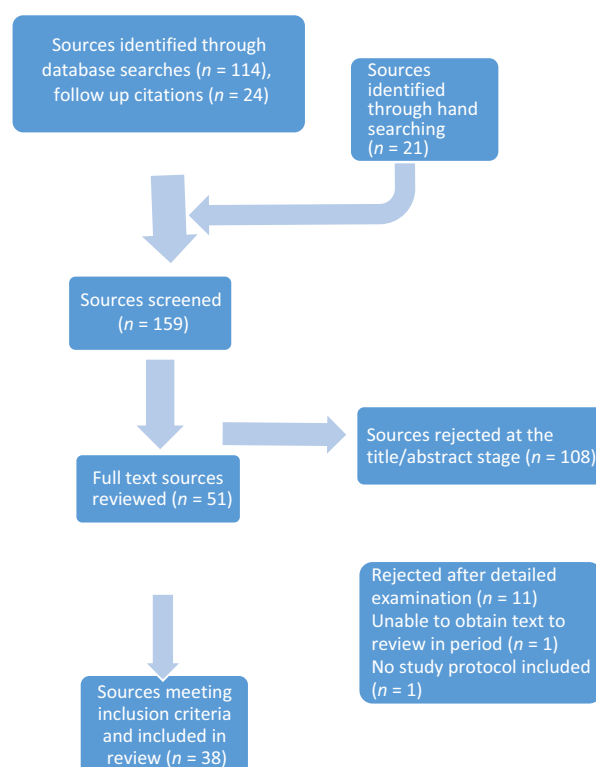


Figure 1 Flowchart for Literature selection.

Review's and Meta-Analysis) was adopted whereby each title, abstract and data presented was reviewed in line with the agreed inclusion criteria. At this stage, each paper was assessed for relevance and quality in order to reduce bias by at least two members of the team allowing opportunity for discussion when uncertainty arose about inclusion.

Findings

The review identified 38 sources describing 33 studies which met our inclusion criteria. Of the 38 sources, 24 were qualitative in design mainly utilising interviews (focus groups and individual) and/or referring to cases, 1 action research methodology and 2 were mixed methods (using quantitative data and interviews). A further five studies were quantitative in design, three were case note reviews and a further three were literature reviews (see Table 1).

The majority of participants within the 33 studies were healthcare professionals (570 from 22 studies) with sources also including service users (128) or family carers (204) with a further 28 participants from third sector organisations. Fifty-four professionals working in other settings (i.e. safeguarding co-ordinators, social workers, social care staff) were also included in the review.

Table 1 Table of included studies

Maps onto descriptive theme		Study aims	Design and sample	Setting	Summarised findings
Author (year)					
Alonzi <i>et al.</i> (2009)	1, 2	To explore views of adult community services healthcare staff	Quantitative (survey data)	Adult Community services	12 areas that staff identified as requiring further guidance and training on the Act.
Bisson <i>et al.</i> (2009)	2, 3	To develop a care pathway for advance decisions and powers of attorney	Qualitative (individual interviews)	Specialist disease unit	A care pathway was developed incorporating education sessions as a new intervention
Bond and Lowton (2011)	1	To establish geriatrician's views on advance decisions (ADRTs)	Qualitative (individual interviews)	6 different acute settings	Findings highlighted a disparity with general supportive views of ADRT and the clinical use of ADRTs.
Boyle (2013)	3	To examine the social process of everyday decision-making by couples living with dementia	Qualitative (observations and individual interviews)	Service users from one local health authority	The spouse-carers generally involved their partners with dementia in everyday decision-making processes.
Dening <i>et al.</i> (2012)	3	To explore whether people with dementia and their carers were able to generate and prioritise preferences for end-of-life care (EOL)	Qualitative (nominal group techniques)	Memory service in 1 NHS Trust	Quality of care, family contact, dignity and respect were ranked as significant themes with three overarching themes (quality of care, independence and control and carer burden)
Dickinson <i>et al.</i> (2013)	3	To understand how Advanced Care Plans (ACP) are understood and utilised with a diagnosis of dementia	Qualitative (variety of interviews)	Older people's services	People with dementia and their families do appear to make some plans for the future (practical, personal, financial and legal). Highlights a number of practical and conceptual tensions faced by professionals when assessing the capacity of dementia patients to make decisions about where to live on discharge.
Emmett <i>et al.</i> (2013)	1, 2, 3	To compare clinical practice regarding assessments of capacity for residency decisions	Qualitative (observations, interviews, focus groups)	3 hospital wards	With a primary focus on training issues of delivery and content were evident, with organisational factors relating to training and then implementation of the knowledge gained.
Gough and Kerlin (2012)	1,2	To evaluate the impact of training within older persons' care homes and the Act	Qualitative [individual and focus group (fg) interviews]	Care homes within 1 local authority	Best interest concepts were reported as part of daily practice but limited understanding of the Act formulation for best interests, highlighting patients best interest may not directly reflect the Act guidance.
Harris and Fineberg (2011)	1	To explore palliative care Multidisciplinary Teams (MDTs) implementation of the concept of 'best interest' decision-making as laid out in the Act	Qualitative (individual interviews)	Community services	

Table 1 (continued)

Author (year)	Maps onto descriptive theme		Study aims	Design and sample	Setting	Summarised findings
	1, 2	3				
Haw and Stubbs (2010)	1, 2		To review the literature on covert medicines administration to older people	Literature review	Any population of older adults in any setting	The review identified 25 papers, 9 articles and 1 inspection copy. In nursing homes disguising medication was common in nursing homes and some institutional patients were receiving medication covertly. Incomplete documentation was apparent.
Livingston <i>et al.</i> (2010)	3		To identify common difficult decisions made by family carers on behalf of people with dementia	Qualitative (individual and fg interviews)	Community settings (GPs, memory clinics, community clinics)	Family carers identified five core problematic areas of decision-making (accessing dementia related health and social services, care homes, legal-financial matters, non-dementia-related healthcare, making plans if the carer becomes too ill to care).
Luke (2008)	2		To examine attitudes to the Act and statutory Independent Mental Capacity Advocate (IMCA) service	Mixed methods (quantitative case referrals and interviews)	7 pilot IMCA services	Clinicians were generally negative about the contribution that IMCAs could make to a patient's medical care.
Manthorpe and Samsi (2012a)	1		To examine the relevance and use of the Act for people with dementia, carers and practitioners	Part 1 of a literature review		Three key studies on specific aspects of the Act are summarised: independent advocacy, best interest and safeguarding provisions.
Manthorpe and Samsi (2013)	1, 2		Literature review on practice in a variety of settings in relation to the Act	Part 2 of a literature review	Variety of healthcare settings (hospital, care homes, people's own homes)	The paper reports on different dementia related interventions in relation to the Act; information and advice, public knowledge, EOL and deprivation of liberty safeguards.
Manthorpe <i>et al.</i> (2009)	3		To seek views and experiences by adult safeguarding co-ordinators regarding the Act	Qualitative (telephone interviews)	Local authority safeguard teams	The study reports the Act was central to the participants safeguarding role. There was general concern that there was insufficient publicity about the Act.
Manthorpe <i>et al.</i> (2009)	3		To gain the views of carers and people with experiences of using services	Qualitative (individual interviews)	Patient and Public Interest group (PPI)	Overall the data suggested that Act was welcomed for its empowering ideals but there were reservations about some of the implications.

Table 1 (continued)

Maps onto descriptive theme		Study aims	Design and sample	Setting	Summarised findings
Author (year)					
Manthorpe <i>et al.</i> (2011)	1,2	To identify knowledge and abilities of care home staff to incorporate the legal framework	Qualitative (interviews)	5 care homes	Regardless of the knowledge of the Act, the daily working ethos of staff appeared to be within the remit of the Act. Considerable variation in the understanding of the terms and principles of the Act was found. They report that voluntary staff largely report how beneficial the Act is for those with dementia in exercising their rights and carers. However, there is a presumption that all staff would have detailed knowledge about the Act and their capabilities and interest may vary.
Manthorpe <i>et al.</i> (2012a)	1	To identify specific challenges faced by staff of local voluntary organisations with the Act	Qualitative (interviews)	Voluntary sector	Five themes were explored (incidence of financial abuse, impact of dementia on safeguarding responses, warning signs of financial abuse, encouraging preventative measures, barriers and facilitators. HCPs need to be more aware and alert to financial abuse of patients with dementia.
Manthorpe <i>et al.</i> (2012b)	2,3	To explore the experiences and views of Adult Safeguarding Co-ordinators (ASCs) focusing on financial abuse of people with dementia	Qualitative (interviews)	Local authority adult safeguarding co-ordinators	The findings indicate that having personal caring experiences may help dementia care practitioners to have more empathy with carers, and the provision of timely information and advice.
Manthorpe <i>et al.</i> (2012c)	1	To investigate the views of dementia professionals who had also provided personal care to a family member	Qualitative (interviews)	Community and care home setting	The paper reports greater awareness and greater confidence of using the principles of the Act.
Manthorpe <i>et al.</i> (2012d)	1	To explore understanding, over time, practice experience of the implementation of the Act	Qualitative (interviews)	Community services	Findings update on reflections of the Act, personalisation, knowledge and familiarity.
Manthorpe <i>et al.</i> (2013)	1,2,3	To investigate the views and experiences of ASCs	Qualitative (interviews)	Local authority adult safeguarding co-ordinators	The paper described 3 basic types of decision-making that emerged (i) legalistic (ii) actuarial (iii) rights-based.
McDonald (2010)	2,3	Explore the impact of the Act on social work assessments of capacity and best interests decision-making	Qualitative (case review with interviews)	Community services	

Table 1 (continued)

Maps onto descriptive theme		Study aims	Design and sample	Setting	Summarised findings
Author (year)					
Phair and Manthorpe (2012)	1,2	A review of hospital policies and practices in safeguarding	Qualitative (document review, file review and interviews)	1 NHS Acute Hospital Trust	Review highlights that the required shifting of culture and embedding of a new approach require a multi-faceted approach that had not previously been considered.
Redley <i>et al.</i> (2009)	3	Evaluation of the pilot IMCA service	Mixed methods (quantitative case referrals and interviews)	7 IMCA pilot projects	Findings indicate more than half of clients were able to provide some indication of their wishes, enabling them to participate directly in personal decisions that they were able to make autonomously.
Robinson <i>et al.</i> (2013)	2	To explore professionals experiences on the implementation of ACP	Qualitative (individual and fg interviews)	Mixed settings (primary care trust, acute trust, ambulance service, voluntary sector, local authority)	While professionals agreed that ACP was a good idea in theory implementation in practice presented them with significant challenges.
Samanta (2012)	2	To explore the views and perceptions of lawyers and health professionals to attorney decision-making at end of life	Qualitative (fg interviews)	Two professional groups (HCP and Lawyers)	The findings indicate that participants gave a guarded welcome to the introduction of healthcare and welfare attorneys, potential challenges were identified, based upon professional norms and expectations.
Samsi and Manthorpe (2011)	3	To explore experiences, opinions and attitudes of older adults for planning their future	Qualitative (interviews)	Service users	Findings revealed that most individuals had a personal tendency for preference towards planning, guided by personality, beliefs, living situation and the relevancy of planning to their situation. Overall few individuals had heard of the Act and were unsure where to turn for help and advice.
Samsi and Manthorpe (2013)	3	To explore everyday decision-making in people's own home	Qualitative (interviews)	Service users	3 underlying core principles framing decision-making arose: 1 – maintaining autonomy 2 – decision-specific approach 3 – decisions made on behalf was in their best interest.

Table 1 (continued)

Maps onto descriptive theme		Study aims	Design and sample	Setting	Summarised findings
Author (year)					
Samsi <i>et al.</i> (2011a)	1	To explore experiences of specialist community nurses providing information about the Act	Qualitative (individual interviews)	Specialist community nurse service	Findings reported participants' knowledge acquisition and training, alongside limited confidence with implementation; practice experiences in the community and the empowering nature of the Act; practice expectations and challenges with implementation.
Samsi <i>et al.</i> (2011b)	1	To explore the role of staff in providing timely information and advice relating to ADM	Qualitative (interviews)	Voluntary sector	Findings suggest that staff had varied knowledge of the Act and most lacked confidence in providing detailed advice.
Schofield (2008)	2	To explore the knowledge of physicians and psychiatrists regarding accessing capacity within the Act	Quantitative (survey)	1 large teaching hospital	This study reports that psychiatrists do slightly better in answering questions about the Act and about capacity when compared with physicians; however, both groups could improve their knowledge.
Seymour <i>et al.</i> (2010)	1,2	To examine how community palliative care nurses understand ACP and their roles within ACP	Action research	Community cancer networks	They report that nurses understood that ACP was an important area of practice and central to good nursing care. They perceived challenges to ACP as: timing, how to effect team working in ACP, the policy focus on instructional directives which relates poorly to patients' concerns; managing differences in patients' and families' view.
Shah <i>et al.</i> (2009)	1	To explore the experience of clinicians working in old age psychiatry	Patient case notes	2 mental health Trusts	The main finding indicated the criteria used for the assessment of DMC and the determinations of best interests were those described in the Act and the accompanying Code of Practice.
Shah <i>et al.</i> (2010)	1	To ascertain the experiences difficulties and the positive experience of implementing the Act	Qualitative (survey)	Old age psychiatrists (different settings)	11 categories of difficulties and 9 categories of positive experiences were reported in the paper.
Sorinmade <i>et al.</i> (2011)	1	To evaluate health professionals fidelity to the Act and principles of determining best interest decisions	Retrospective review of patient notes	1 NHS Trust	The study reported the difficulty to locate relevant entries as there was no designated folder for MCA issues.

Table 1 (continued)

Author (year)	Maps onto descriptive theme	Study aims	Design and sample	Setting	Summarised findings
Willner <i>et al.</i> (2011)	1	To assess the extent of knowledge of the Act among new recruits to a NHS Trust	Quantitative (questionnaire)	1 NHS Trust	While respondents knowledge appeared reasonably good for some important features of the Act these results may have been exaggerated by a strong desire to appear true. Findings show that staff generally had a good understanding of the issues around capacity but felt unclear about some aspects of the Act (and its terminology). Some guidance suggested for HCP on when and how to approach the issues with patients and or carers.
Wilson <i>et al.</i> (2010)	2	To gain an understanding of professionals' knowledge of the Act in relation to ACP	Qualitative (fg, individual, and telephone interviews)	3 specialist palliative care units and 3 neurological units.	

From the 38 sources meeting our inclusion criteria, thematic analysis was applied (Pope *et al.* 2006) with each researcher (KHS, GW, RF) independently coding the data. Descriptive themes were brought together and synthesised to provide three overarching themes: (i) Knowledge and understanding of the Act; (ii) Implementation and tensions in applying the Act; and (iii) Alternative perspectives of the Act. These descriptive themes demonstrate the range of understanding of the Act across a range of professional disciplines and the application of the Act to healthcare practice.

Table 1 provides details for the 38 identified sources along with indication of its relevance to the three key descriptive themes described.

Knowledge and understanding of the Act

Twenty-two studies covering a range of healthcare settings and professionals where the Act may be applicable were identified. Authors report that while there has been statutory training delivered in relation to the Act, there appears to be variable understanding of the full complexities of the Act on the part of health and social care professionals across England and Wales.

Statutory training on the Act

Of the 22 studies included in this theme, 15 explored staff training and understanding of the Act. These studies covered different settings and professional groups, for example clinicians (Shah *et al.* 2009, 2010, Bond & Lowton 2011, Sorinmade *et al.* 2011), care home staff (Manthorpe *et al.* 2011), community healthcare staff (Alonzi *et al.* 2009, Manthorpe *et al.* 2012d) and voluntary organisations (Samsi *et al.* 2011b, Manthorpe *et al.* 2012a).

The findings from these studies indicated that staff had received MCA (2005) training as required by the Department of Health (2006) but this appears to provide a theoretical understanding of the principles of the Act rather than their application to practice, for example in a care home setting (Gough & Kerlin 2012) or working in a palliative care team (Harris & Fineberg 2011). This suggests that training needs to go beyond simply knowing about the Act to being able to apply it in everyday practice, regardless of the setting, as part of a planned CPD programme (Haw & Stubbs 2010, Manthorpe *et al.* 2011).

Studies reported that initial training was substantially funded (Manthorpe & Samsi 2012a) and offered across all English and Welsh NHS Trusts (Willner *et al.* 2011) but the training was unlikely to assess the retention of the material (Willner *et al.* 2011), or more

importantly evaluate the application of the Act into clinical settings (Willner *et al.* 2011). Work undertaken by Shah *et al.* (2009, 2010) did indicate clinician's adherence and compliance to the Act in clinical settings as did work by Manthorpe *et al.* (2012c). However, Sorinmade *et al.* 2011 conducting a hospital case records review reported 'patchy documentation of the legal criteria used in capacity assessment', and furthermore 'clinicians only partially followed the procedure prescribed by the MCA in determining best interest' (p. 174).

Variable knowledge of the Act by healthcare professionals

Six studies highlight a variable understanding of the Act and its application to practice on the part of healthcare staff (Alonzi *et al.* 2009, Harris & Fineberg 2011, Samsi *et al.* 2011a, Phair & Manthorpe 2012, Emmett *et al.* 2013, Manthorpe & Samsi 2013). Findings from these studies noted that staff had some comprehension of the Act and held favourable views of the Act (Alonzi *et al.* 2009, Samsi *et al.* 2011a) but a number of staff were still unclear about aspects of the Act, for example assessing capacity and patient decision-making (Alonzi *et al.* 2009) and implementation (Samsi *et al.* 2011a). Phair and Manthorpe (2012) reported that all healthcare professionals had knowledge of the Act but the level of knowledge varied with almost two-third of respondents lacking confidence in their understanding of the Act.

Implementation and tensions of applying the Act

The review identified 15 studies, across a range of clinical settings and professional staff groups that explicitly described the challenges associated with implementing the Act into clinical practice.

Translating the Act into clinical practice

Despite evidence of training on the Act, there were difficulties of translating the principles of the Act, often taught in a class room, to the real-life world of clinical practice (Phair & Manthorpe 2012, Samanta 2012). For example, Schofield (2008) reported that of the 32 physicians and 20 psychiatrists completing a questionnaire related to familiarity of the Act, overall knowledge on aspects of mental capacity was lacking (p. 116).

The review also highlighted a wide variation in the implementation of the Act in different care settings and in relation to different health and social care needs. For example, decision-making processes covered under the premise of the Act were found to be different between hospital-based and community-

located palliative care services within one area (Wilson *et al.* 2010). When dealing with place of residence, Emmett *et al.* (2013) reported that professionals had difficulty reconciling what they referred to as patients' unwise decisions and the need to respect these views and that this tension was more troublesome for junior nursing staff. Furthermore, there was notable reporting of failures to adopt a consistent approach to determining patients' decision-making capacity with patient non-compliance or disagreement often identified as a trigger for capacity assessment (Emmett *et al.* 2013). One study suggested that staff working in acute settings may be less confident and skilled in working with the Act than other specialist teams (Phair & Manthorpe 2012). There were also reported differences between safeguarding coordinators and other healthcare staff as a result of instances when the Act may be applicable and part of everyday roles and responsibilities (Manthorpe *et al.* 2013). Wilson *et al.* (2010) described this as instances where there may be less opportunity to 'get to know' the patient or access key patient information.

Tensions in applying the Act to everyday clinical settings

Nine studies highlight how staff often struggled to assimilate and apply the principles of the Act into their work settings, especially in relation to small or everyday acts of care (Luke 2008, Alonzi *et al.* 2009, Bisson *et al.* 2009, Manthorpe & Samsi 2013, Robinson *et al.* 2013). For example, Robinson *et al.* (2013) explored the implementation of Advanced Care Plans (ACPs) in dementia and palliative care settings from the perspective of 95 professionals across a range of settings. They reported that there was a general agreement, by staff, for the principle of ACPs as empowering individuals to make healthcare choices. However in reality, the myriad of care decisions that healthcare professionals may consider for the patient provides ambiguity for when the principles of the Act are applicable (Robinson *et al.* 2013) and may provide ethical difficulties between clinical decisions and adhering to wishes that may be legally binding and included in the ACP. Bisson *et al.* (2009) highlights that often clinical management decisions occur when a patient no longer has capacity and therefore is unable to proceed documenting an ACP.

Work conducted in other healthcare settings, i.e. care homes (Manthorpe *et al.* 2011, Gough & Kerlin 2012) and palliative and neurology care centres (Wilson *et al.* 2010), also note the complexity of clinical and care decisions that staff face daily, especially in relation to everyday acts of care. For example, Alonzi *et al.* (2009) reports that where there is no clear threshold for the nature of decisions and where staff

are encouraged to conduct 'situation-specific assessments' (p. 25), this may lead to misunderstanding of the application of the Act for everyday decisions. The nature of subjectivity in assessing individuals' capacity in line with the Act is not confined to healthcare settings. McDonald (2010) conducted work on social workers' decision-making and noted that it was particularly troubling for staff when considering future place of residency against balancing an individual's right to independence.

Alternative perspectives of the Act

The review identified 12 studies that reported the views of non-healthcare professionals, including informal family carers (9), well older people (1) and staff working in third sector organisations (2) who provide help and support to frail older people (e.g. Age Concern, Alzheimer's Society).

A further five studies sought views of other professionals, for example safeguarding co-ordinators and Independent Mental Capacity Advocate (IMCA) services. Within this theme, two dimensions of perspectives from these groups of individuals were observed; a general lack of understanding about the Act and when the Act becomes relevant.

Nine studies sought the views of family carers providing ongoing everyday care for a spouse. The predominant cognitive disease was a diagnosis of dementia (Livingston *et al.* 2010, Denning *et al.* 2012, Boyle 2013, Dickinson *et al.* 2013, Emmett *et al.* 2013, Samsi & Manthorpe 2013) or other neurodegenerative disease (Bisson *et al.* 2009). Within these nine studies, there was a prominence of including the person with the diagnosis within the study protocol (Boyle 2013, Dickinson *et al.* 2013, Emmett *et al.* 2013, Samsi & Manthorpe 2013, Denning 2012, Bisson *et al.* 2009) providing a different insight into the awareness of the Act, and one study was conducted with self-declared well older people (Samsi & Manthorpe 2011).

The studies provide strong evidence of the difficulties experienced by carers who provide long-term health and social care for a family member and the challenges associated with decision-making when fluctuating capacity is a factor (Livingston *et al.* 2010). While there was some comprehension of the Act by family carers, this tended to be focused on specific aspects, for example financial planning and powers of attorney (Samsi & Manthorpe 2011, Manthorpe *et al.* 2012d) with less evidence of health and welfare plans (Samsi & Manthorpe 2011, Denning *et al.* 2012). There was less explicit knowledge about the Act by carers or spouses (Bisson *et al.* 2009,

Boyle 2013) with carers often reliant on professionals to make decisions (Denning *et al.* 2012). For example, Denning *et al.* (2012) exploring end-of-life decisions for people with dementia noted that some concepts of dignity and respect under the Act were difficult to comprehend and were often discussed with a professional once a patient had lost capacity. While relatives are often involved in the decision-making process (Livingston *et al.* 2010, Boyle 2013, Dickinson *et al.* 2013) their limited understanding of the Act means that dealing with difficult emotive decisions, such as end-of-life plans or future residency can create tensions with other family members (Samsi & Manthorpe 2011, Manthorpe *et al.* 2012b, Dickinson *et al.* 2013).

The five sources that sought the views of those providing other services such as safeguarding leads (Manthorpe *et al.* 2009, 2012b, 2013), IMCA service (Redley *et al.* 2009) or social workers (McDonald 2010) provide a different perspective to the establishing and understanding of the Act by these professionals. The work by Manthorpe *et al.* (2009, 2012b, 2013) explored the implementation of the Act with a focus on safeguarding individuals with dementia. Their work emphasises a greater need to support people 'at risk' either at diagnosis of a neurological disease so that they are less likely to face abuse, including financial (Manthorpe *et al.* 2012b), as their condition progresses and affects their cognitive abilities. The limited understanding of the Act by the public at large often places safeguarding co-ordinators in a position of trust providing an overview of the Act for carers while working with other professional groups (Manthorpe *et al.* 2009). The work conducted by Redley *et al.* (2009) aimed to evaluate a new IMCA service for those lacking capacity without family or friends across seven pilot projects. In reviewing referrals, they were able to identify that the scheme provided support for individuals with dementia or learning difficulties who might have limited comprehension of the Act to make autonomous decisions (Redley *et al.* 2009).

Discussion and conclusions

The review identified 38 sources describing 33 studies which collectively provide a broad evidence base relating to the implementation of the principles of the Act in clinical health and social care practice. The review includes 12 studies that sought the views of carers and individuals with dementia or cognitive disease and five sources that sought the views of other professionals where the Act informs part of their role. The review identified three overarching

themes relating to implementation of the Act with specific reference to the care of frail older people. These were the inherent tensions between requirements of the Act and its implementation in the everyday realities of clinical practice, the limited effectiveness of current approaches to education and training about the Act and its application and the lack of knowledge and awareness about the Act on the part of lay and informal carers.

The studies tended to conclude that the principles of the Act were welcomed, but the findings consistently demonstrated the need for a broader understanding, better conceptualisation and improved processes to incorporate the requirements into care provision (e.g. Emmett *et al.* 2013, Robinson *et al.* 2013). Very few studies examined interventions that aimed at enabling practitioners to adopt the principles of the Act (Bisson *et al.* 2009, Boyle 2013) or facilitating service users to engage with their ACPs (Dening *et al.* 2012).

The evidence available would suggest that there are inconsistencies in the application of the Act across a variety of care settings. Professionals are shown to be utilising elements of the principles of the Act, such as ACPs, and best interest decision tools to support decision-making with frail older people. However, confusion regarding the Act remains, in both providers, recipients of care and third sector organisations providing advice and guidance. The review findings would concur with those conducting work with older people and carers (Manthorpe *et al.* 2011, Samsi *et al.* 2011a,b) that a wider understanding of the Act is required. A national public campaign for older well people as well as individuals who have received a recent diagnosis linked to the new UK Dementia Strategy (Department of Health 2013) would be timely considering the emphasis for greater understanding of the condition and long-term health consequences.

The review has highlighted that while training regarding the Act has been provided, there remain shortfalls in how this learning is applied to practice. This review suggests staff need more opportunities to engage, learn and implement the Act, in order for it to have greater resonance to their individual practice and benefit patient care (Manthorpe *et al.* 2012a, Emmett *et al.* 2013). This aspect of staff understanding of the Act may be a reflection of the inclusion dates covered in this review where there was an initial emphasis in ensuring that all healthcare staff were aware of the legislative powers of the Act and a paucity of empirical studies providing evidence about to offer solutions to embedding the principles of the Act into everyday practice (Seymour *et al.* 2010).

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